

NPM #6: The percentage of youth with special health care needs who received the services necessary to make transition to all aspects of adult life. (CSHCN Survey)

Impact on National Outcome Measures: Baseline Data

- SLAITS Data indicate that only 7.41 % of Wisconsin youth with special health care needs report that they are receiving services necessary to make transitions to adult life.
- Other potential data sources:
 - ◆ The HRTW Project is a demonstration project. The project's total count of all youth served from July 1, 2001 to March 3, 2003 is 68.
 - ◆ The current state MCH data system does not provide transition related data. Although the SPHERE data system scheduled for start up in 2003, will provide youth/adult transition service related queries as a system enhancement.

a) Report of 2002 Major Activities

1. Partnership between CSHCN Program and Healthy and Ready to Work (HRTW) designee—Infrastructure Building Services—CSHCN

As Wisconsin Title V MCH/CSHCN Program CSHCN designee, the Waisman Center for Developmental Disabilities is one of five recipients of the HRTW MCHB-funded demonstration grants. The Waisman Center is also the site of one of the five Regional CSHCN Centers. Collaborations include using the Regional CSHCN Center 800 line as a Statewide HRTW/Transitions I&R "hotline", and including the Regional CSHCN Centers' participation in the Waisman HRTW Project funded and facilitated interagency Statewide Transition Consortium for key stakeholders. The CSHCN Regional Centers are working with communities, health care providers, post secondary educators, and employers to support youth and their families during transition to adult health care, education and work experiences.

2. Healthy and Ready to Work Outreach—Population-Based Services—CSHCN

Continuation of the CSHCN Program's long-term support and co-sponsorship of the annual statewide Circles of Life Conference for Wisconsin parents and providers which, beginning in 2002, included a "for youth only" concurrent conference aimed at enhancing youth leadership, self-care and self-advocacy skills.

3. Healthy and Ready to Work Training—Infrastructure Building Services—CSHCN

The HRTW project conducted local community trainings on transition through the IEP and self advocacy to high school students and teachers. The HRTW Project established a statewide Youth Advisory Council, which meets quarterly.

4. State Partnership Building—Infrastructure Building Services—CSHCN

State partnership building include planning with state SSA representatives and other DHFS programs to streamline the reevaluation aspects of the transition from the state's TEFRA waiver (aka Katie Beckett Program) to SSI eligibility at age 18; the CSHCN Program serving on the DHFS TBI Advisory Committee; and the CSHCN Program serving as a major participant to a DHFS draft report entitled "Prevention of Adolescent Pregnancy in Wisconsin: Recommendations Related to Youth with Disabilities".

b) Current 2003 Activities

1. Partnership between CSHCN Program and Healthy and Ready to Work (HRTW) designee—Infrastructure Building Services—CSHCN

The CSHCN Program, both directly and through the TA it provides to the five Regional CSHCN Centers it monitors and funds with the state's Title V MCH/CSHCN Program Block Grant dollars, continues to partner with its HRTW designee, the Waisman Center in the ongoing activities listed above.

2. Healthy and Ready to Work Outreach—Population-Based Services—CSHCN

Two statewide educational teleconferences were provided by the CSHCN Program for Regional CSHCN Center staff, local public health nurses, school personnel, health care providers, and other local service providers: a) January 15, 2003: SSI for Kids: Helping Families apply for and Maintain Eligibility and b) May 15, 2003: The Basics of Adolescent Transitions for Youth with Special Health Care Needs.

Regional CSHCN Centers have initiated documentation of: a) Transition related services and resources they provided to youth and families, either directly or through their contracted service coordination/case management agencies (usually LPHDs) and b) Regional youth/family transition resource and service needs (including those that go unmet) as identified by families, youth, and service providers in their respective regions.

3. State Partnership Building—Infrastructure Building Services—CSHCN

As follow up to recommendations made in the previously mentioned paper on adolescent pregnancy prevention among disabled youth, the HRTW Project has been invited by the DHFS Title V MCH/CSHCN Program/MCH state adolescent health consultant to present this July 2003 at Wisconsin's Annual Teen Pregnancy Prevention and Intervention Conference.

HRTW Project is providing valuable input regarding youth transition related data elements to be included in the new SPHERE data system Wisconsin will be implementing in 2003.

The SPHERE data system will be used by all entities receiving Title V MCH/CSHCN Program dollars, e.g., LPHDs and the five Regional CSHCN Centers. Once transition data elements are added, the CSHCN Program will be able to establish a baseline for NPM#6 and to track

Wisconsin's progress as transitions to adult health care, education/training, community living, and work improve for youth with special health care needs.

c) 2004 Plan/Application

1. Partnership between CSHCN Program and Healthy and Ready to Work (HRTW) designee—Infrastructure Building Services—CSHCN

All activities listed for 2002 and 2003 will continue into 2004 with the following modifications, expansions or enhancements: a) The HRTW Project will expand trainings across the state for person-centered life planning and self-determination; for self care/self-advocacy; and for other transition related topics, b) A steam-lined SSI reevaluation process for "Katie Beckett Program" eligible youth turning 18 is planned for piloting and possible expansion to include SSI eligible youth turning 18, and c) Youth on the HRTW Project's Youth Advisory Council plan to establish a speakers' bureau.

2. Healthy and Ready to Work Outreach—Population-Based Services—CSHCN

The CSHCN Program, the five Regional CSHCN Centers it monitors and funds, and the HRTW Project will continue to work together with families, youth and other transition stakeholders, collaborating to increase public awareness and to provide training on transition topics such as early life/vocation planning, assuming responsibility for one's health, access to quality, person-centered health care, and the impact of chronic illness and disability on human growth and development including sexual awareness.

3. State Partnership Building—Infrastructure Building Services—CSHCN

The CSHCN Program is participating in the Medical Home Learning Collaborative through the NICHQ. The HRTW Project will share with the three pediatric practices participating as Medical Home Pilot Site transition-related expertise and insights, and in turn, HRTW will learn from the pediatricians what knowledge and resources they need to help the youth in their practices with chronic illnesses and disabilities plan with for transitioning to adult health care and other services.

HRTW Project will be collaborating with the University of Wisconsin Children's Hospital Pediatric Pulmonary Center, a pediatric specialty clinic and University of Wisconsin Medical School training site and recipient of several MCHB grants over the years to develop a survey of transitions—related services provided by U.W. Children's Hospital.

The five Regional CSHCN Centers will collect transitions related data using a tool designed by HRTW project which will meet interim data collection needs until transition elements can be added to the SPHERE data system.

The Regional CSHCN Regional Centers will designate a "Transition Liaison" to participate with HRTW and the CSHCN Program in an information sharing network.